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Patient Autonomy and the Right to Die

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TRS 340 Bioethics: Religious Approaches

Professor Latela

Abstract

The Patient Bill of Rights grants protection for patient autonomy, the right to accept or refuse treatment, while the principles of beneficence and nonmaleficence, or doing no harm, is tightly held by medical clinicians. However, when doing what the patient wants is not in accord with what the physician believes is right and good, ethical conflicts arise. In the case of Mr. Roberts (anonymized), treatment for Cushing Syndrome had been completed but left him bed-ridden and connected to a ventilator, with no specific timeline predicted for recovery. Having experienced an ongoing series of refractory events, Mr. Roberts had grown weary of the suffering his “cure” had precipitated, and he expressed his wish to die. Ethical precedence already exists regarding the discontinuation of life-sustaining treatment in the setting of terminal illness or a persistent vegetative state, but can a competent patient refuse life-sustaining interventions as a means to end the suffering brought about from treatment? This case study examines the ethical dilemma.

Patient Autonomy and the Right to Die

The Consumer Bill of Rights and Responsibilities, adopted by the US Advisory on Consumer Protection and Quality in the Health Care Industry in 1998, addresses in its key areas taking part in treatment decisions: “You have the right to be informed about your treatment options and take part in decisions about your care. You have the right to ask about the pros and cons of any treatment, including no treatment at all. As long as you are able to make sound decisions, you have the right the refuse any test or treatment, even if it means you might have a bad health outcome as a result” (cancer.org, 2014). When the patient’s choice to refuse treatment will result in death, conflict arises between autonomy and beneficence. When treatment is complete but not completely curative, the balance between autonomy and beneficence becomes even more skewed. “The dialogue between autonomy and beneficence is ages old. Doing what the patient wants is not always consonant with doing what one believes is good and right for the patient. Inner conflict for the physician lies on both sides of this issue. It is just as hard to live with giving the judgmentally competent patient the right not to be treated when the outcome of treatment is likely to be good as with doing everything possible for a patient, predicting or even promising a good outcome, only to have the actual outcome make one question the quality of that saved life” (Daly, Gokhale, and Ramos-Estebanez, 2014). When there is diminution in the quality of life, does a patient have the right to die?

Mr. Roberts was admitted to a venerated teaching hospital after being worked up by a general practitioner for fatigue and weakness. An elevated cortisol level led to a suspected diagnosis of Cushing Syndrome, and magnetic resonance imagine was questionable for a pituitary gland tumor. Near the end of a surgical procedure to biopsy the tumor, Mr. Roberts experienced a traumatic extubation, could not be successfully reintubated and required emergent

surgery for placement of a tracheostomy. Transsphenoidal tumor resection is a highly specialized procedure, and there was only one surgeon who performed this surgery at the hospital.

Unfortunately, this surgeon was undergoing knee surgery shortly after the biopsy. Mr. Roberts had another surgical procedure to place a percutaneous endoscopic gastrostomy (PEG) tube and then was sent to a rehabilitation center for weaning off the ventilator. A long series of refractory episodes continued to plague Mr. Roberts. He became septic in rehab, and was readmitted to the Medical Intensive Care Unit (ICU). While there, he experienced a mechanical fall while working with Physical Therapy. Three months after the initial biopsy, he was able to have the pituitary tumor resected and came to the Neuroscience ICU post-operatively. After caring for him for three consecutive shifts, I signed up as his Primary Nurse. Mr. Roberts had grown diffident of many of the care providers, but trusted me. He had remained on the ventilator the entire time, unable to tolerate the weaning mode (continuous positive airway pressure, CPAP) for more than thirty minutes. This made it impossible for Mr. Roberts to speak, but he wrote recurrently in journals. Endocrinologists struggled to normalize his hormone levels, and further workup determined that an adrenalectomy could further address his Cushing Syndrome. Postoperatively Mr. Roberts was experiencing intense physical pain that prevented him tolerating lying flat, and involved a torticollis-like neck stiffness.

It was now six months since the biopsy. In that time, Mr. Roberts had not been able to speak, eat, walk, sleep comfortably, see his beloved cat, and more importantly, leave the ICU. I entered his room alone and he wrote, "Help me." When I asked how I could help him, he wrote, "I want to die." I could see Mrs. Roberts approaching the room, so I pulled the curtain and asked him to tell me more. When he finished, I asked if I could share his statements with his wife, who was also a nurse. He agreed. The three of us sat in silence for a short while and then decided it

was time to approach the attending physician. Mr. Roberts wrote of his suffering, of the lack of any quality of life and any promise of quality. Mr. Roberts wanted to go home to die. The attending physician placed a consult to the Ethics Committee.

The Consumer Bill of Rights and Protection safeguards Mr. Roberts' right to refuse treatment, even though in this case treatment had essentially been completed. He was being followed by three services – neurosurgery, endocrinology, pulmonology – all of whom had determined that there were no more interventions other than to allow Mr. Roberts' body to normalize, strengthen, and wean him from the ventilator. "There is ethical and legal consensus that a patient has the right to refuse life-sustaining treatment (LST), as an expression of autonomy-based principles, when the patient demonstrates an appropriate degree of capacity, the decision is consistent with the patient's preferences and free from coercion, and when the burdens exceed the benefits of continued treatment. Patients can request to discontinue LST for any number of reasons, some of which are ethically relevant. For instance, sometimes a patient refuses LST because of an inherent belief that maintaining current and foreseeable aggressive interventions constitutes an unacceptable quality of life" (Peña, 2015).

The Ethics Committee met privately with Mr. Roberts before questioning his family or any of his caregivers. Additionally, Mr. Roberts' pastor was brought in to discuss his desire to die. The committee then interviewed his physicians, myself, his wife and two sons. Among the committee's priorities was determining Mr. Roberts' capacity to make this decision. "While the right to withhold and withdraw life-sustaining treatment (LST) has been clearly established in American law, medicine, and ethics, clinicians and families hold to the time-honored principles of beneficence and nonmaleficence, in their desire to protect even the 'autonomous' patient from short-sighted, poorly considered decisions that can cut a life short, if there is any way to avoid

doing so in a situation where all believe that the patient can get better. Depression does not always preclude capacity for specific medical decisions, but it can lessen second-level autonomy—which is the ability to reflect critically upon current wishes with the ability to change such wishes in light of more important preferences and values. Capacity to appreciate knowledge is more than just what one knows or understands about treatment choices and their consequences; it is how those choices and consequences are believed and what they mean, when applied to the personal, lived situation” (Leslie and Robinson, 2015). The Ethics Committee had determined that Mr. Roberts had capacity to make this choice and had taken all aspects of his decision into consideration, even at a metaphysical level.

In a group meeting with all of the mentioned parties to Mr. Roberts’ care, all of the physicians maintained that Mr. Roberts had been cured. But when asked how long it would be until Mr. Roberts could exact any normalcy in the quality of his life, no one was able to offer a predictable time line. Six months to a year were suggested. Mr. Roberts was in a form of medical purgatory. “Since none of us are very good at predicting the future, we have all probably travelled this road to medical purgatory. We have traversed this path either as a personal journey or as a guide with patients and family members under our care. Our patient arrived here by following the rules of the road, seeking the best of medical opinions, choosing options that were reasonable, receiving excellent care, and encountering surprises that were not predictable” (Brown and Galanos, 2015). The meeting dispersed and the committee adjourned to determine if Mr. Roberts would be permitted to go home to die.

The Ethics Committee was given a daunting task. There are no cut and dry normative theories that dictate an obvious resolve. A Utilitarian approach would allow Mr. Roberts to die if certain criteria were met. From the Utilitarian perspective, the right action would be whatever

results in the greatest amount of happiness to the greatest number of people involved. “Thus if the person wanted to die, and less family members objected that agreed, the mercy killing would be ok. However, if more family member objected, the Utilitarian would push the principles of the Utilitarian approach back on the family members to ask what would result in the greatest amount of happiness. In this case, the unnecessary suffering of a family member that will inevitably result in death is not choosing to produce happiness. Thus the conclusion would be to allow the mercy killing” (Cohen-Almagro, 2008). Mrs. Roberts, as a nurse and nurse educator, was advocating for her husband, promoting his wishes above her own. She would often say that she felt the physicians blamed her for allowing the events to unfold. From a Kantian perspective, allowing Mr. Roberts to die would not be the right thing to do as it would create a new acceptable behavior of murder, an exception to a universal law. Kantian philosophy believes in retributivism: murder is approved when one is convicted of killing another, taking into consideration the specific circumstances involved when taking a life. Retributivism ignores the specific circumstance of needless suffering and the request of someone wanting to die. Deontologists would also not approve of allowing Mr. Roberts to die, as they maintain that the killing of innocent humans is strictly prohibited. “Deontology prohibits only active killing. It is compatible with this doctrine that we allow people in poor countries to starve to death while we are living comparatively well. Even some kinds of active killing can be morally acceptable (and required) as long as it was not intended. For example, it may be morally permitted to give a patient a painkiller that kills her if the intention is to kill the pain not the patient. The death of the patient is then a foreseen but not desired consequence of the action. Similarly it is permissible to withhold nourishment from a patient in a persistent vegetative state and allow them to die” (Tännsjö, 2005). Deontologists may struggle with the fact that the actual mechanism of Mr.

Roberts' proposed death would not be active on behalf of the physicians; Mr. Roberts would voluntarily stop artificial nutrition and hydration, disconnect the ventilator, and progress to death. But deontology makes no moral distinction between murder and suicide, thus determining that allowing Mr. Roberts to die would be morally wrong.

Catholic teaching authority has addressed the moral issues concerning artificial nutrition and hydration (ANH) in the Ethical and Religious Directives (ERD) for Catholic health services. Specifically, ERD 58 states that "in principle, there is an obligation to provide patients with food and water, including medically assisted nutrition and hydration for those who cannot take food orally. This obligation extends to patients in chronic and presumably irreversible conditions (e.g., the 'persistent vegetative state') who can reasonably be expected to live indefinitely if given such care. Medically assisted nutrition and hydration become morally optional when they cannot reasonably be expected to prolong life or when they would be 'excessively burdensome for the patient or [would] cause significant physical discomfort, for example resulting from complications in the use of the means employed.' For instance, as a patient draws close to inevitable death from an underlying progressive and fatal condition, certain measures to provide nutrition and hydration may become excessively burdensome and therefore not obligatory in light of their very limited ability to prolong life or provide comfort" (United States Conference of Catholic Bishops, 2009). From the standpoint of this ERD, there is no justification in withdrawing ANH from Mr. Roberts as he is not suffering from "an underlying progressive and fatal condition"; his suffering is existential.

Most, if not all normative theories regarding the right to die are guided by the sanctity of life. The argument exists from one side, which maintains that man has complete authority over his life (autonomy) and the other side, which asserts that life is sacred and must be preserved at

all costs. “This argument is equally problematic because it limits human choice and could hold us hostage to the many medical technologies available today that have the ability to stave off death while also imposing significant burdens and increasing patient suffering. A more balanced Christian view holds neither extreme to be true, recognizing both a duty to preserve life and reasonable limits to this duty” (Panicola, et al, 2011).

The Ethics Committee ruled in favor of Mr. Roberts and his request to go home to die. Palliative care was brought on board to his medical team, and the goals of care made the transition from recovery in the hospital to optimizing his condition in order to be stable enough to go home. Ironically there was little difference between the two; a primary focus was weaning Mr. Roberts from Assist Control mode to CPAP mode on the ventilator. Going home with a ventilator was not an option. We worked closely with Respiratory Therapy to strengthen Mr. Roberts’ respiratory status and find a vendor who could merge a CPAP machine with a tracheostomy. We trained Mr. Roberts’ wife and sons on the use of the PEG tube, feeding pump, and tracheal suctioning equipment. Mr. Roberts’ mood was decidedly lighter, his anxiety lower, and seemed more engaged with his family and with some of his healthcare team. “Patients’ awareness of their continuing power to control this important aspect of life, despite the constraints posed by serious illness, can be in itself therapeutic” (Berry, 2009). Two weeks later Mr. Roberts left the Neuro ICU and returned home.

Visiting Nurses who administered medication, respiratory therapists who maintained the CPAP device and stocked oxygen, hospice nurses, clergy, friends and family, supported Mrs. Roberts and the care of her husband. “Whichever transfer approach is adopted, there are a core set of needs to be met for all dying patients in their own home including: good symptom control; confident and committed general practitioners; access to specialist palliative care; effective co-

ordination of care; and education of what to expect when someone is dying. In critical care there is a growing body of work to guide the management of a 'good death'. In practice there is a need for clear and respectful interdisciplinary communication to facilitate effective planning for end of life care. Involving the patient, the family and significant others, and all key health care staff in discussions about care requires the intelligent and compassionate use of nursing skills. Through this, the experience of patients and families during end of life care can be improved" (Tele, Pyle, and Coombs, 2012).

Two weeks after returning home, Mr. Roberts wrote, "I think it's time to stop the tube feeds and water," and made a similar statement three days later regarding the CPAP device. Hospice care managed his comfort, and he passed peacefully at home, surrounded by his family, his cat, his books, and his music collection, on his own terms. As Brown and Galanos (2015) stated, "You see, you cannot leave purgatory unless you get well or unless you turn off the vehicle that is keeping you there."

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